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ABSTRACT

This Policy Research Brief summarizes longitudinal national statistics on the number and characteristics of persons with mental retardation and related conditions living in state institutions, their movement into and out of those institutions, the costs of state institutions, and the growing numbers of closures of these institutions. Findings are based on data collection by the National Data Set Project on Residential Services located at the University of Minnesota. The brief uses narrative, tables, and graphs to specifically address the following: historical patterns of deinstitutionalization; the total residential care system; resident characteristics (functional assistance needs, age, secondary conditions); resident movement (patterns, characteristics of movers, previous and subsequent residences); state institution costs; and state institution closures (past and projected closures, and selected state plans and policies on closure). The continuing commitment of states to the depopulation and closure of state institutions is projected, with continuing challenges in providing adequate resources for community services for those with high support needs. It is predicted that increasing cost inefficiencies of under-utilized state institutions will lead to even more closures of such institutions. (DB)

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Policy Research Brief

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Persons with Mental Retardation and Related Conditions in State Institutions: Trends and Projections

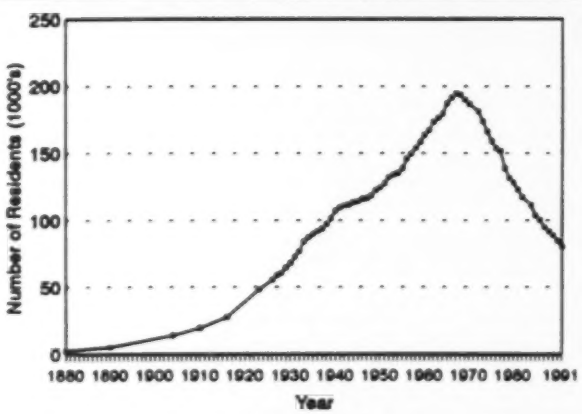
This issue of Policy Research Brief summarizes longitudinal national statistics on the number and characteristics of persons with mental retardation and related conditions living in state institutions, their movement into and out of those institutions, the costs of state institutions, and the growing phenomenon of state institution closures. The findings are based on data collection by the National Recurring Data Set Project on Residential Services, a project of the Research and Training Center on Residential Services and Community Living, Institute on Community Integration (UAP), University of Minnesota.

■ Deinstitutionalization: Historical Patterns

State institutions as residences for persons with mental retardation and related conditions have been operated in the United States for nearly 150 years. From the establishment of the first state institution for persons with mental retardation on the grounds of Massachusetts' state school for the blind in 1948, the population of state institutions for persons with mental retardation and related conditions grew steadily through 1967 when it reached an average daily residential population of 194,650 people. Since 1967 the United States has been engaged in a major effort to depopulate state mental retardation/developmental disabilities (MR/DD) institutions and to close them. Additionally, a steady annual decrease of 3% to 6% has been evident every year since, with average daily populations of state MR/DD institutions reaching 80,269 in Fiscal Year 1991. As shown in Figure 1, this was the lowest average daily population since 1932.

While state MR/DD institution population reductions have been quite steady and relatively steep over the past 25 years, if one examines the reduction in populations of persons with mental retardation and related conditions in both MR/DD and psychiatric state institutions, the rates of decline are even more remarkable. As shown in Figure 2, the number of persons with a primary diagnosis of mental retardation and related conditions in state psychiatric hospitals increased from 1950 (23,905) to 1961 (41,823), and then began to steadily decrease. By 1967 the total number of persons with mental retardation and related conditions in state MR/DD and psychiatric institutions had reached the highest total ever at 228,500 (194,650 in state MR/DD institutions, 38,850 in state psychiatric hospitals). Since then, the decreases have been much more rapid in the state psychiatric institutions, which by 1991 had only 1,594 residents with a primary diagnosis of mental retardation and related conditions.

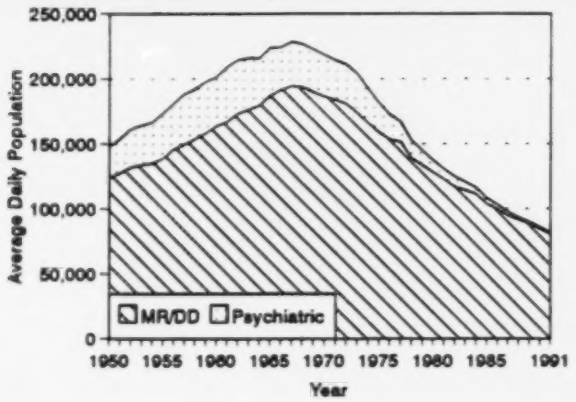
Figure 1: People with Mental Retardation and Related Conditions in State MR/DD Institutions, 1880-1991



A summary of research on policy issues affecting persons with developmental disabilities. Published by the Research and Training Center on Residential Services and Community Living, Institute on Community Integration (UAP), College of Education, University of Minnesota.

EC 303019

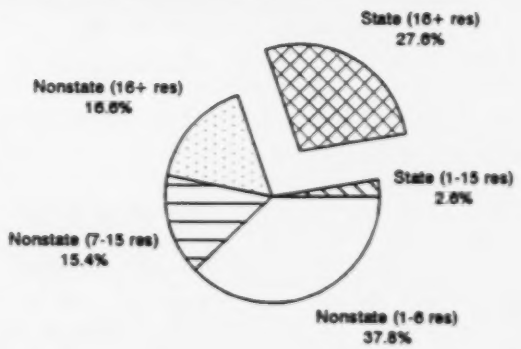
Figure 2: Average Daily Population of Persons with Mental Retardation and Related Conditions in State MR/DD and Psychiatric Institutions, 1950-1991



■ Total Residential Care System

Through depopulation, state institutions are becoming a smaller part of the total system of residential services for persons with mental retardation and related conditions. In June, 1967, state MR/DD institutions housed 88.4% of all persons who received state-operated or state-licensed residential services for persons with mental retardation and related conditions. In June, 1977, that figure had fallen to 62.4%, and in June, 1987, it was 37.2%. In June, 1991, as shown in Figure 3, state MR/DD institutions housed 27.6% of persons receiving state-operated or state-licensed residential services for persons with mental retardation and related condition.

Figure 3: Size of State Institution Populations (16+ Residents) as Compared with Populations of Other State Operated or State Licensed Residential Facilities in June, 1991



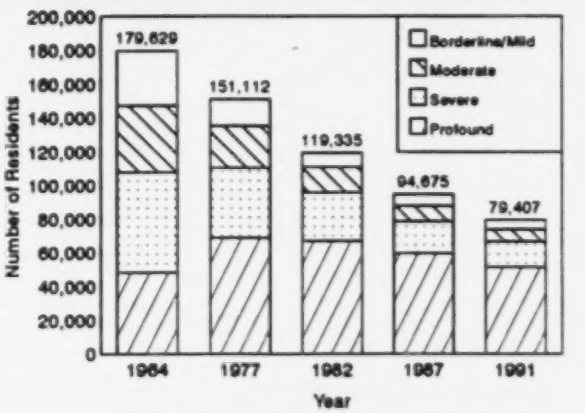
■ Resident Characteristics

Not only is the total size of the residential population of state MR/DD institutions steadily changing, but so are the characteristics of that population. Figure 4 summarizes changes in the level of mental retardation of residents between 1964, just before the beginning of state MR/DD institution depopulation nationwide, and 1991.

In 1964, only 48,500 (27%) of the 179,600 state MR/DD institution residents had profound mental retardation. By 1977, there were 68,900 persons with profound mental retardation living in state MR/DD institutions, making up 46% of all state MR/DD institution residents. During this same period the number of state institution residents with mild, moderate, and severe mental retardation decreased by 48,900 persons.

By June, 1982, the number of persons with profound mental retardation in state institutions had decreased by 1,800 to 67,100 people and made up 56% of all residents.

Figure 4: Level of Retardation of Residents of State Institutions on June 30 of Selected Years, 1964-1991



Between 1982 and 1987 the number further decreased to 59,700 persons, which was 63% of all residents. Between 1987 and 1991 the number of people with profound mental retardation in state institutions decreased by another 8,200 to about 51,500 people, or 65% of all residents. Between 1964 and 1991 the proportion of state MR/DD institution residents with severe mental retardation decreased from 33% to 19%; with moderate retardation, from 22% to 9%; and with mild or no mental retardation, from 18% to 7%.

Functional Assistance Needs

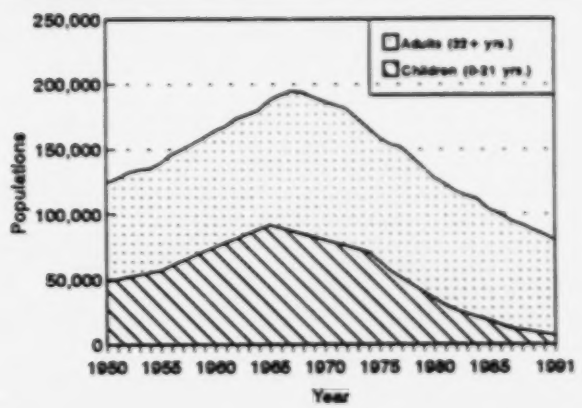
In 1991, 32.8% of all state MR/DD institution residents were reported to be unable to move about without the

assistance of another person. This was a somewhat higher percentage than had been reported in earlier years and reflects a slow but steady increase in the proportion of residents with ambulatory limitations. Although greater, the proportion of residents with needs for assistance in moving from place to place in 1991 (32.8%) was not dramatically greater than the 31.2% reported in 1989, the 29.5% in 1987, the 25.5% in 1982, and the 23.3% in 1977. Similarly, while the majority of 1991 state MR/DD institution residents (54.1%) were reported to be able to toilet themselves independently, there has been a slow increase in the proportion of residents who need assistance in toileting. The percentage of residents needing assistance with toileting increased only from 34.1% in 1977 and 38.0% in 1982, to 46.4% in 1987 and 45.9% in 1991. Again despite increases in the proportion of state MR/DD institution residents who need assistance in basic functions such as mobility and toileting, over the past 14 years the actual number of state institution residents with such limitations has actually decreased rather substantially. For example, in 1991 there were about 25,700 persons needing ambulatory assistance as compared with about 35,200 in 1977. In 1991, there were about 36,500 persons needing assistance with toileting as compared with about 51,500 in 1977 .

Age of Residents

There has been a clear commitment in recent years to reduce the number of children and youth in out-of-home residential placement, especially placements in large institutions. The most dramatic result of this commitment has been the reduction by nearly 90% in the number of children and youth 21 years and younger in state MR/DD institutions between 1965 (91,592) and 1991 (6,944) (see Figure 5). In fact the number of children and youth in state institutions in 1989 was lower than the number of children and youth in state MR/DD institutions in 1904 (8,053) when the total state institution population was only 13,884 persons of all ages. In 1965, children and youth 21 years or younger made up nearly half (48.9%) of the 187,305 state institution residents; in 1991 children and youth made up only 8.7% of all state institution residents. The decrease in children and youth has been much more rapid than the decrease in adult populations. In 1965 there were 95,713 adults (22 years or older) in state institutions; in 1991 there were 73,325. The largest population of institutionalized adults occurred in 1968 (109,022). As of June 30, 1991, there were 11 states with no state institution residents 14 years or younger; there were three with no residents younger than 22 years.

Figure 5: Total and Childhood (0-21 Years) Populations of State Institutions, 1950-1991



Secondary Conditions

Severe sensory impairments are increasingly common among state institution residents. In 1991, 12.3% of state institution residents were reported to be functionally blind. This compared with 11.8% in 1989, 10.2% in 1985, 9.4% in 1982, and 6.0% in 1977. More than 10% of state institution residents in over 60% of states were functionally blind. In 1991, nationally, 5.6% of state institution residents were reported to be functionally deaf. This compared with 5.6% in 1989, 4.9% in 1985, 4.7% in 1982, and 3.6% in 1977. A majority of states reported fewer than 3% of their state institution residents to be functionally blind.

In 1991, increasing proportions of state institution residents were also reported to have neurological disorders. Nationwide, 44.6% of state institution residents were reported to have seizure disorders. This compared with 42.5% in 1989, 35.9% in 1985, 33.9% in 1982, and 32.5% in 1977. State institution residents in 1991 were also more likely to have cerebral palsy. In 1991, 21.6% of residents nationwide were reported to have cerebral palsy. This compares with 21.3% in 1989, 19.0% in 1985, 18.7% in 1982, and 18.6% in 1977.

The proportion of residents reported to exhibit behavior disorders also continued to increase, reaching almost half of the resident population. In 1991, it was reported that 47.8% of state institution residents had behavior disorders. This compared with 46.6% in 1989, 38.8% in 1985, 36.0% in 1982, and 25.4% in 1977. In all, 56.7% of all state institution residents were reported to have at least two of the above conditions in addition to mental retardation in 1991. This, too was an increase over previous years: 54.6% in 1989, 39.7% in 1985, 37.6% in 1982 and 35.1% in 1977. However, again the total number of 1991 residents reported to have each of these conditions was less than the total reported in 1977.

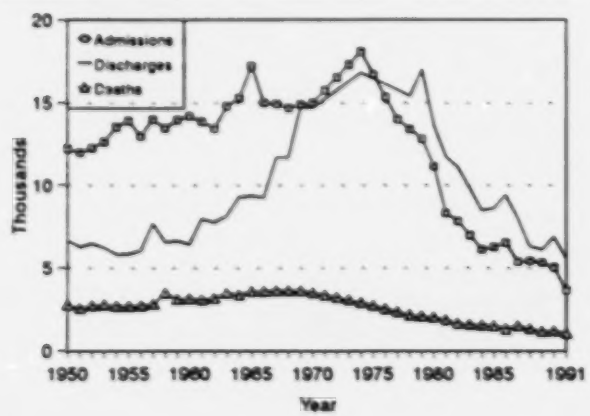
■ Resident Movement

Patterns of Movement

From the beginning of this century until the mid-1960s, statistics on persons moving in and out of state MR/DD institutions were relatively stable. During that period first admissions and discharges both steadily increased, but state institution populations grew as first admissions substantially outnumbered discharges. During this same period readmissions remained relatively low because once placed in a state institution, people tended to remain there. From 1903 to 1965 state institution death rates decreased steadily from 4.1% to 1.9% of the average daily population. By FY 1978 death rates had fallen to 1.6% and have remained in the range of 1.3% to 1.6% since (1.3% in 1991).

By the mid-1960s these historical patterns began to change. In 1965, the number of first admissions to state-operated facilities began to decrease, dropping below the increasing number of discharges by 1968. The number of readmissions increased substantially throughout the 1970s as return to the institution was a frequently used solution to problems in community placements. Since 1980 readmissions have been reduced fairly steadily, but remain a substantial proportion of total admissions (35.7% in 1991; 35.3% in 1990). During this same period total admissions (first admissions and readmissions) generally remained fairly consistently between 2,000 and 3,000 fewer than the number of discharges. The difference was 1,843 in FY 1990 and 1,887 in FY 1991. Figure 6 shows these trends for the period 1950 to 1991. Because of differences among surveys in defining transfers, first admissions, and readmissions, all types of admissions have been combined.

Figure 6: Movement Patterns in State MR/DD Institutions, 1950-1991



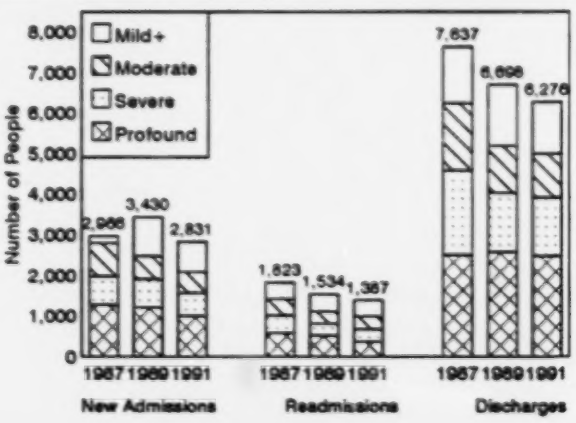
The data show that overall admissions to state institutions decreased rather dramatically during FY 1991 to 3,654 persons, 1,380 fewer than in FY 1990. In 1991 total discharges (5,541) were about 14% lower than the annual average for the previous three years.

Deinstitutionalization may literally connote discharging people from institutions, but from Figure 6 it is clear that reducing admissions to state institutions has actually accounted for relatively more of the reduction in state MR/DD institution populations than has the number of discharges. From 1979 to 1991 there were substantial decreases in both admissions to (from 12,802 to 3,654) and discharges from (from 16,980 to 5,541) state institutions.

Characteristics of Movers

The number of people moving into and out of state institutions has been decreasing for over a decade. The people with mental retardation and related conditions moving into and out of state MR/DD institutions are substantially less cognitively impaired than other state MR/DD institution residents. Figure 7 compares the number and distribution by level of mental retardation of newly admitted,

Figure 7: Distribution of Admissions and Discharges for State Institutions by Level of Mental Retardation, FY 1987, 1989, and 1991



readmitted, and released residents of state institutions in Fiscal Years 1987, 1989, and 1991.

Admission patterns were generally similar in 1987, 1989 and 1991, although there were somewhat fewer persons in each of these categories. In 1991, total admissions (new admissions and readmissions) were 11.9% fewer than in 1987 and 15.0% fewer than in 1989. Discharges were 17.8% fewer in 1991 than in 1987, and 6.3% fewer than in 1989. As noted above this general pattern of decreasing movement into and out of state institutions has been evident for many years. The level of mental retardation of persons in

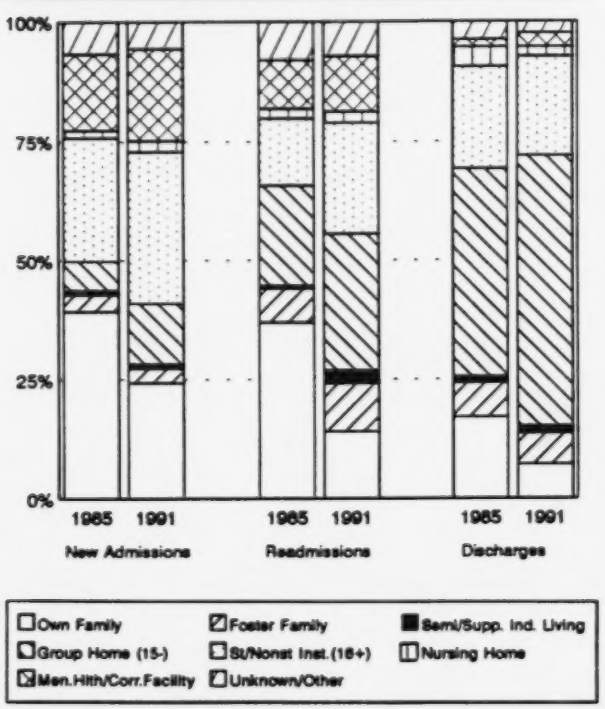
movement has been remarkably consistent across movement categories (i.e., new admissions, readmissions and discharges) and across years (1987, 1989 and 1991). In 1991, 35.4% of new admissions, 26.5% of readmissions and 39.4% of discharges were persons with profound mental retardation as compared with 64.8% of the general population.

Previous and Subsequent Residences

Between 1985 and 1991, new admissions were most likely to come from public or private MR/DD institutions (31.7%). Readmissions were most likely to come from community group homes or board and care arrangements of 15 or fewer total residents. Most persons discharged from state institutions moved to community group homes or board and care arrangements (56.8%). Figure 8 shows the proportion of state institution new admissions and readmissions coming from different places of residence and the proportion of discharges going to different kinds of residences.

Between 1985 and 1991 there was a very substantial decrease in the extent to which natural or adoptive families were involved in any category of movement. There was a decrease from 39.2% to 24.2% in the proportion of new admissions coming from their families, and from 36.8% to 14.1% in the proportion of readmissions coming from their own homes. State institution residents being discharged to their own homes decreased from 17.1% to 7.1% of all discharges. Obviously these changes derive in large measure from the substantial commitment toward reducing the use of state institutions for children and youth since historically most persons entering state institutions from their families and returning to their families after discharge have been children and youth.

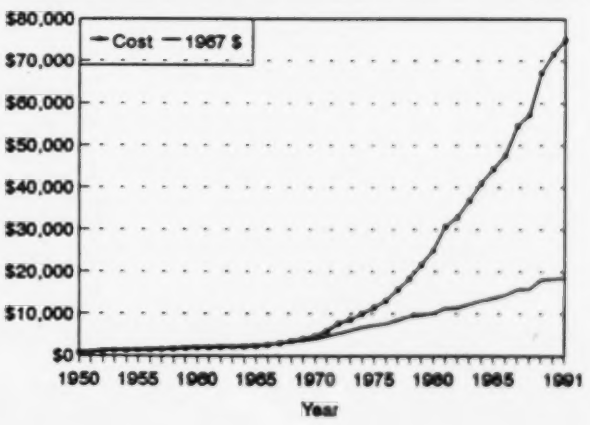
Figure 8: Previous/Subsequent Residence of Persons Moving Into and Out Of State Institutions, 1985 and 1991



State Institution Costs

The cost of care provided in state institutions has increased dramatically since 1950, and especially in the past 20 years. In 1950 the average per person annual cost of care was about $745.60 (or $2.04 per day). By 1991 the average annual cost had risen to $75,051.30 per person (or $205.62 per day). In dollars adjusted for changes in the Consumer Price Index over this period, cost of care in 1991 was 18 times as great as in 1950. Figure 9 shows the trends in state institution costs in both nominal and inflation adjusted dollars ($1=1967) between 1950 and 1991. In terms of 1967 "real dollar" equivalents, the average annual per person cost of care in state MR/DD institutions increased from just over $1,000 to over $18,500 during the 41 year period. That rate of increase represents an annual after inflation compounded growth of 10% per person per year. However, in the last two years, the rate increases have slowed substantially to 1.35% in real dollars between Fiscal Years 1989 and 1990, and 1.10% in real dollars between 1990 and 1991. This compares with an average of 8.1% annual real dollar increase during the 1980s.

Figure 9: Average Annual Per Resident Costs of Care in State MR/DD Institutions, 1950-1991



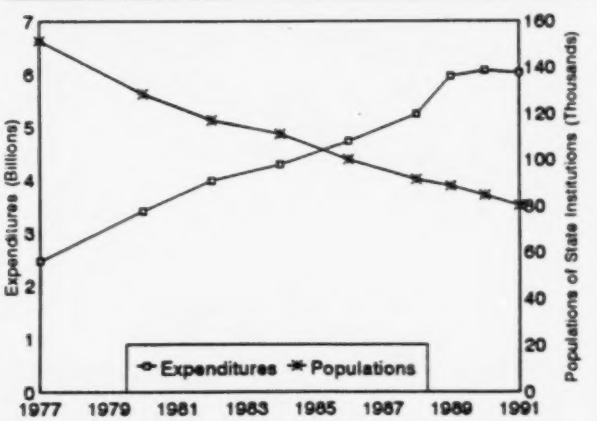
A number of factors have contributed to the steady increases in the costs of state institution care. One

contributing factor has been the steady increase in more severely impaired resident populations. Associated with these changes have been increased staff to resident ratios and increased numbers of professional staff.

Legislative and judicial requirements for upgrading the physical and program quality of state institutions have also contributed to costs. Two major factors appear to have contributed clearly to the cost of care since the early 1970s. The first of these was the creation of the Intermediate Care Facility for the Mentally Retarded (ICF-MR) program in 1971. It offers federal Medicaid cost-sharing of 50% to 80% of state institution costs, depending on the per capita income in states, under the condition that facilities meet specific program, staffing, and physical plant standards. By 1991, 19 of every 20 state institution residents lived in units with ICF-MR certification. The ICF-MR program has significantly cushioned the impact of rapidly increasing institution costs for the states. For example, in 1970, one year before enactment of the ICF-MR program, the average annual per resident cost of state institution care was about $4,000. In 1991, with the average annual per resident real dollar cost at $18,500 ($14,500 more), states' shares of the increase were on average only about $4,200 per resident per year. Court decisions and settlement agreements have also had significant impact on the costs of public institutional care nationally with their frequent requirements of substantial expenditures by states to upgrade staffing levels, add programs, and improve physical environments, along with frequently required reductions of institution populations.

It has been the decrease in institutionalized populations with neither reductions in institution budgets nor substantially reduced number of institutions that has directly driven the steady increase in per resident costs. Figure 10 shows both the decreasing populations of state institutions and their increasing annual expenditures between 1977 and 1991. Fiscal Year 1991 represents somewhat of a milestone in that for the first time since the early years of the Great Depression (i.e., 1929-1933) the total annual expenditure for state MR/DD institutions in the United States decreased. This outcome was achieved because states are increasingly turning to the total closure of institutions as the only effective means of controlling state institution expenditures and freeing revenues that can follow deinstitutionalized individuals as they move into the community.

Figure 10: State Institution Average Daily Populations (Thousands) and State Institution Expenditures (Billions), 1977-1991

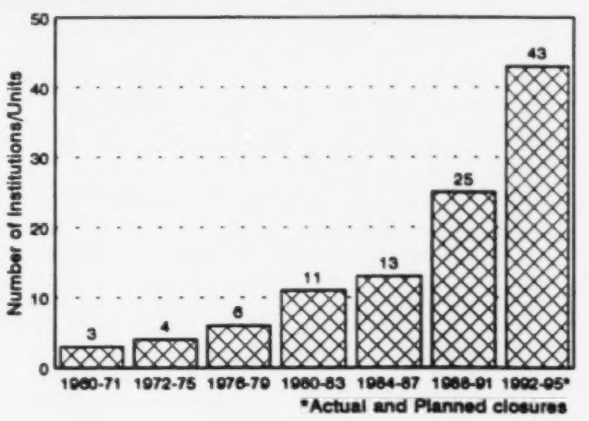


State Institution Closures

Past and Projected Closures

The United States is entering a period of substantial reduction not only of the populations of state institutions, but also of the number of institutions actually in operation. While populations have been declining for a quarter century, actual closures of institutions were relatively rare until the last few years. States project that closures will be frequent in the next few years. Figure 11 shows the number of closures of state MR/DD institutions and MR/DD units in other state institutions from 1960 through 1995 (projected). Between 1960 and 1971 only three state MR/DD institutions or MR/DD units were closed in the United States, an average of 0.25 per year. In the 4-year period between 1972 and 1975 there were a total of four closures, an average of one per year. Every subsequent 4-year period experienced a somewhat greater rate of institution closures: There were six between 1976 and 1979 (an average of 1.5 per year), 11 between 1980 and 1983, and 13 between 1984 and 1987 (annual averages of 2.75 and 3.25, respectively). Between 1988 and 1991

Figure 11: Numbers of State MR/DD Institutions and Units Closed and Planned for Closure, 1960-1995



closures increased rapidly to 25 (6.25 per year). In 1992 there were 11 institution closures with 32 others planned by the end of 1995 (an average of 10.75 per year from 1992 to 1995). According to current plans, by the end of 1995 three states (New Hampshire, Michigan and Vermont) will have no state MR/DD institutions or units with 15 or more residents. The majority of states (32) have either closed a state MR/DD institution or are planning to do so by the end of 1995. Twenty states plan to close at least one institution between 1992 and 1995; only six of these states have not previously closed a state MR/DD institution.

Selected State Plans and Policy on Closure

As noted above, about two-thirds of all states have already closed and/or will soon be closing one or more state MR/DD institutions. Other states are examining scenarios for state institution closures beyond 1995. The following briefly describes the plans and deliberations taking place in a number of states that are considering the roles of their various state institutions in the future of their residential services systems:

- **New York.** It is the stated policy of the New York Office of Mental Retardation and Developmental Disabilities that all of New York's Developmental Centers will be closed by the year 2000. New York's experience of closing six institutions between January 1988 and December 1992 has provided substantial experience in implementing such a policy. In addition to the Long Island and Bronx Developmental Centers closed in 1992, New York has identified five additional state institutions that are likely to be closed by the end of 1995. New York state has negotiated an agreement with state employee unions whereby virtually all individuals leaving the institutions being closed will enter residential programs staffed by state employees. Daytime employment and development will be available from both public and private providers.
- **Michigan.** In 1992, Michigan closed three state institutions (Muskegon, Newberry and Oakdale) to continue a trend that included six state institution closures in the previous 10 year period. Michigan is left with three state institutions (Caro, Mt. Pleasant and Southgate) with plans to close each by the end of 1994.
- **Texas.** Closure of at least one Texas State School for persons with mental retardation was a condition in a 1991 settlement agreement in a long-standing lawsuit over the conditions of Texas state residential services. In 1992, the state created a new position of Assistant Deputy Commissioner of Mental Health/Mental Retardation specifically to coordinate the closure of two Texas' state schools (Fort Worth State School and Travis State School). Closure committees and work groups have been created within both of the target state institutions to develop plans, and internal and external procedures and programs to carry out the closures.
- **New Hampshire.** In January, 1991, with the closure of Laconia State School and Training Center, New Hampshire became the first state in the United States to have no residents in state institutions. State officials report that there was never an articulated state policy to close Laconia. Instead its closure was the natural result of a state commitment to provide all Laconia residents with the highest quality and most integrated lifestyles that were available to them.
- **Minnesota.** In 1989, the Department of Human Services presented the legislature with a long-range plan, negotiated with state employee unions and key advocacy groups, that would effectively close Minnesota's seven remaining state institutions by 1999. The plan called for relatively few persons (100-150) to continue receiving services at the existing institutions. State employees would have been involved in providing services to approximately 600 persons. Implementation of the negotiated agreement does not appear to be a commitment of the present administration, but it has proposed to the current legislature the closing of two institutions by 1994.
- **Massachusetts.** In 1991, Massachusetts established a plan for consolidation of state institutions, including closure of at least three. The Massachusetts Department of Mental Retardation negotiated an agreement with state employee unions for the continued involvement of state employees, including state operation of community residential programs serving at least 350 people and day programs serving at least 50 people. The state projects closure of MR/DD programs at Denver Hogan/Berry, Medfield, and Worcester Regional Centers by 1995.

■ Conclusion

Across the country, states continue to act out a national commitment to the depopulation and closure of state institutions. Although the statistics on state institution depopulation remain among the important indicators of the changes taking place in the housing and residential services available to persons with mental retardation and related conditions, they are an increasingly smaller part of the total picture. On June 30, 1991, while 79,407 persons with mental retardation and related conditions were living in state institutions (80,903 persons counting those in psychiatric facilities without specialized MR/DD units), there were 209,963 persons with mental retardation and related conditions living in smaller state facilities (15 or fewer

residents) and in nonstate residential settings for persons with mental retardation and related conditions. Of these individuals, 48,001 were residents of nonstate institutions with more than 16 residents. Another 37,817 persons with mental retardation and related conditions not counted in the above statistics were residents of Medicaid certified nursing homes, a statistic that has changed relatively little in recent years despite the OBRA 1987 requirements for review of the appropriateness of nursing home placements of persons with mental retardation and related conditions. While 56.0% of the 289,370 persons with mental retardation and related conditions in residential settings in the United States are in places with 15 or fewer other persons with mental retardation and related conditions, only 38.1% (110,111) are in settings of a more typical family scale of six or fewer total residents. Including nursing and state psychiatric institution placements, less than half (49.2%) of persons with mental retardation and related conditions in residential settings are in places of 15 or fewer residents, and barely one-third (33.4%) are living in settings of six or fewer residents with mental retardation and related conditions.

Major changes continue to take place in the ways that residential services are provided to persons with mental retardation and related conditions. Major challenges still exist in assuring that all persons have the opportunity to enjoy the benefits of community living. Among those challenges is assuring adequate resources for community services for the persons with typically high support needs. Increasingly states are recognizing that the only way to finance such services is to continue to move people out of state institutions and to close institutions as the difference between intended capacity and actual utilization creates cost inefficiencies that states are ever less able to afford. ▪

More comprehensive national and state-by-state statistics on utilization of state and nonstate residential services, Medicaid participation, persons waiting for residential services, and related topics are available in the report, "Residential Services for Persons with Developmental Disabilities: Current Status and Trends Through 1991." It is available for $8.00 from the address below. Please make checks or purchase orders payable to University of Minnesota.

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